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Internalized HIV Stigma and Quality of Life among People Living with HIV/AIDS in Aizawl

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Abstract: The current study focuses on identifying the relationship between Quality of Life and Internalized HIV Stigma amongst People Living with HIV/AIDS (PLWHA). The study employed a quantitative approach with an aim to find out the prevalence of Internalized Stigma and to examine the Quality of life among a sample of 50 PLWHA (24 males and 26 females) from Aizawl city. The highest proportion of the sample (52%) falls under the Moderate level of Internalized HIV Stigma. Those experiencing High-Internalized HIV Stigma form the smallest proportion (14%), while 34% of the participants fall under the low-Internalized Stigma level. Statistical analysis revealed that females scored higher in Internalized HIV Stigma than the male population ($p<0.05$). Results also showed that there are significant differences in IHS, on the basis of duration of diagnosis ($p<0.01$) and occupation ($p<0.01$). No significant differences were found in Overall Quality of Life, based on any of the socio-demographic variables. Further analysis indicated that there was a significant negative relationship between Quality of Life and Internalized HIV stigma (-0.440 at 0.001 level).

Keywords: HIV/AIDS, Internalized HIV Stigma, Quality of Life, People Living with HIV/AIDS, discrimination.

INTRODUCTION

Human immunodeficiency virus infection/ acquired immuno-deficiency syndrome (HIV/AIDS) has been one of the greatest health problems in the world since its discovery in the beginning of the 1980s. HIV/AIDS places an increasing burden on health, and causes socio-economic problems for individuals, families, communities, and governments in many countries.

Stigma is not unique to HIV and has been seen throughout history in relation to other diseases, including tuberculosis, syphilis, and leprosy, which are associated with the transgression of social norms. However, studies have shown that the stigma associated with the disease of the human immune system is greater than that of other stigmatized illnesses (e.g., diabetes, epilepsy; Fernandes et al. 2007, 322).

Internalized stigma occurs as an individual internalizes cultural norms and narratives that identify him/her as a member of a deviant group, and assumes a "spoiled identity" (Sayles et al. 2008, 749). When an individual internalizes his/her stigma, he/she denies support financially and socially, which in turn could negatively impact the quality of life (Thomas et al. 2005, 799). In Beau, Cameroon, it has been found that apart from stigma from other people, the internal stigma is the second major problem in dealing with the disease (Jacobi et al. 2011, 175).

Quality of Life in individuals living with HIV/AIDS has become crucial for measuring commonly used endpoints. Quality of Life (QOL) is a term that is popularly used to convey an overall sense of well-being and includes aspects, such as happiness and satisfaction with life as a whole. QOL relates both to the adequacy of material circumstances and to personal feelings about these circumstances with overall subjective feelings of well-being that is closely related to morale, happiness, and satisfaction (Lesserman, Perkins and Evans, 1992). The World Health Organization (WHO) has defined quality of life "as an individual's perception of their position in life in the context

of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO 1997, 1).It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment.

HIV/AIDS stigma can severely compromise the QOL of people living with this condition by reducing access and quality of care. Some studies from India have reported the association between stigma and the Quality of Life (QOL). A clinic based study reported that internalizing of stigma had a significant negative correlation with QOL in the psychological domain and environmental domain (Thomas et al. 2005, 799). Another clinical based study reported that each type of stigma was associated with each domain of QOL (Subramanian et al. 2009).

Aizawl is the capital of the north-eastern state of Mizoram in India. With a resident population of 291,822, it is the largest city in the state. Mizoram, being the third most affected area in India, has witnessed and is experiencing the impact of HIV/AIDS. In Mizoram, the first case of HIV infection was seen in an injecting drug user in October, 1990. Initially, HIV transmission in Mizoram was drug-driven through sharing of infected syringes and needles. Majority of HIV infection occurred among the IDUs and their partners. The 1990s saw the Mizo youths devastated by the twin epidemic of drug addiction and HIV/AIDS. In 1998, an HIV epidemic took off quickly among the state's male injecting drug users, with some drug clinics registering HIV rates of more than 70% among their patients. HIV prevalence at antenatal clinics was 0.75% in 2007 (NACO, 2007). As per the report of Mizoram State AIDS Control Society (MSACS), the number of blood tested since October, 1990 to October, 2013 is 255453 (cumulative), and the number of HIV positive cases is 8516 (cumulative). Among the districts of Mizoram, Aizawl has the second highest HIV population.

The Mizo society is a close-knit one with no class distinction. As the majority of the Mizo people are Christians, the whole society

revolves around the church. Their faith in Christianity influences their outlook and perspectives towards what is right or wrong. The first known cases of HIV in Mizoram were among IDUs and CSW (commercial sex workers). As such is the case, prejudice towards HIV is prevalent. Moreover, HIV has been considered as a form of punishment to those whose lifestyles are considered immoral.

HIV/AIDS has had a great impact on society, both as an illness and as a source of discrimination. The disease also has significant economic impacts. There are many misconceptions about HIV/AIDS such as the belief that it can be transmitted by casual non-sexual contact. It was only a few years ago that the corpse of people who died of AIDS were wrapped in polythene bags and buried as quickly as possible so that other people would not be infected. Though this is no longer the case and much awareness has been given regarding the ways of transmission of this disease, it is still a highly feared illness. The disease has also become subject to many controversies involving religion. AIDS is often seen as *someone else's problem* – as something that affects people living on the margins of society, whose lifestyles are considered immoral. Even as it moves into the general population, the HIV epidemic is still misunderstood among the public. Thus, it may be assumed that the internalization of stigma by PLWHA may be high in Mizoram.

The Present Study

We conducted an analysis of baseline data from a sample of HIV-positive men and women. Using this sample, we examined indicators of internalized stigma among HIV-positive men and women. We were particularly interested in examining the prevalence and degree of Internalized HIV stigma (IHS) experienced as well as the relationship between IHS and Quality of Life (QOL).

Prior research in India has reported that internalizing of stigma had a significant negative correlation with QOL (Thomas et al. 2005, 799). Studies on HIV/AIDS in general and PLWHA in particular are minimal at present in Mizoram. It is, therefore, felt necessary to explore the IHS and QOL of PLWHA in Aizawl. The overall consideration

would not only help satisfy to achieve the theoretical and methodological considerations but would provide foundations for behavioural intervention programs and further extended studies. For this purpose, the present study was designed with the following research questions in mind:

1. How prevalent is IHS in this population?
2. Are there demographic characteristics that distinguish those individuals who may experience a high versus a low level of IHS?
3. Are there demographic characteristics that distinguish those individuals who may experience a high versus a low level of QOL?
4. What is the relationship between IHS and QOL?

METHODS AND PROCEDURE

Sample: Purposive sampling procedure was followed and the sample consisted of 50 PLWHA (24 males and 26 females) from Aizawl city. The background information of the subjects like age, gender, duration of diagnosis, religion, marital status, number of children, educational qualification, occupation and income were recorded.

Research Objective: To study the relationship between IHS and QOL among People Living with HIV/AIDS and to observe if differences exist based on demographic characteristics.

Tools: To meet the objectives of the present study, the Internalized HIV Stigma Measure (Sayles et al. 2008) and the WHOQOL-HIV BREF (WHO, 2002) were used.

i. **The Internalized HIV Stigma Measure** is a 28-item scale that measures Internalized Stigma. The scale consists of 4 sub-scales, namely, Stereotypes of HIV, HIV Disclosure Concerns, Social Relationship Stigma and Self-Acceptance. Responses to each item are on a 5-point categorical response (none of the time, a little of the time, some of the time, most of the time, or all of the time). Total scores can range from 0-100 with higher scores indicative of greater levels of internalized stigma. In this study, the overall stigma scores were categorized into three categories such as no or mild, moderate

and severe stigma using the 33rd and 66th percentile cut off values from the distribution of scores. This categorization was exclusively done for this study.

ii. **The WHOQOL-HIV BREF** consists of 31 items, with each item using a 5-point Likert scale. These items are distributed in six domains. The six domains of Quality of Life are as follows: physical health, psychological health, level of independence, social relationships, environment, and spirituality/religion/personal beliefs. The physical health domain measures pain and discomfort, energy and fatigue, and sleep and rest. The psychological health domain measures positive feelings, thinking, learning, memory and concentration, self-esteem, bodily image and appearance, and negative feelings. The level of the independence domain measures mobility, daily life activities, dependence on medications or treatments, and work capacity. The social relationships domain includes personal relationships, social support, and sexual activity. The environment domain measures physical safety and security, home environment, financial resources, health and social care, accessibility and quality, opportunities for acquiring new information and skills, participation in and opportunities for recreation and leisure activities, and physical environment (pollution, noise, traffic, climate, and transport). The spirituality/religion/personal beliefs domain measures forgiveness and blame, concerns about the future, and death and dying. The domain scores indicate an individual's perception of quality of life in each particular domain. Domain scores are scaled in a positive direction (i.e., higher scores indicate higher quality of life).

iii. **Reliability of instruments:** In the Internalized HIV Stigma Measure, the overall internal consistency (Cronbach's alpha) for the entire 28-item scale was 0.87. The Cronbach's alpha for Stereotypes of HIV, HIV Disclosure Concerns, Social Relationship Stigma and Self-Acceptance was 0.79, 0.95, 0.76 and 0.51 respectively. In WHOQOL-HIV BREF, the overall internal consistency was 0.88. This was 0.75, 0.64, 0.38, 0.25, 0.76 and 0.58 for physical health, psychological health, levelsof independence, social relationships, environment, and spirituality/religion/personal beliefs.

iv. **Analysis of data:** Data were analyzed using the SPSS software (version 19). In the descriptive analysis, Mann Whitney U test and Kruskal Wallis Chi-Square test were used to determine statistical differences in socio-demographic variables (age, gender, duration of diagnosis, marital status, number of children, educational qualification, occupation and income) in the scores of PLWHA in IHS and QOL. Spearman's rank order correlation coefficients were estimated to examine correlations among the four subscales of Internalized HIV Stigma and the six domains of Quality of Life.

RESULTS

Demographic Characteristics of PLWHAs: Table 1 and Table 2 present the socio-demographic characteristics of 50 PLWHA. The study included 24 (48%) males and 26 (52%) females. All the participants in the study were Christians. Among 50 PLWHA, 16% were diagnosed with HIV/AIDS in the year prior to the interview, 34% in the past two or five years, 34% in the past six to nine years, while 16% had been diagnosed more than 10 years ago. More than half of the participants (52%) were married, while 16% of the participants were single, 20% were divorced and 12% had been widowed. A higher proportion of the participants (70%) had children (Table 1). Regarding their Educational Qualification, 4% were illiterate, 8% had studied till Primary School, 30% till Middle School, 34% till High School, 16% till Higher Secondary School, while 8% were graduates. Among the 50 participants, only 16% were unemployed, with the majority (38%) being manual labourers. Social workers were also high in number (32%) while there were very few participants employed by the government (4%). 22% of the participants had no regular income, 36% earned below Rs. 3,000 per month, 30% earned between Rs. 3,000 and Rs. 6,000; 2% earned between Rs. 6,000 andRs. 9,000; 8% earned between Rs. 9,000 and Rs. 12,000; and 2% earned more than Rs. 12,000 per month.

Internalized HIV Stigma among PLWHA in Aizawl: The Prevalence of IHS among PLWHA is presented in Table 3. The highest proportion of the sample (52%) falls under the Moderate level of IHS. Those experiencing High IHS form the smallest proportion (14%), while 34%

of the participants fall under the Low IHS. The mean Internalized stigma score was found to be 43.89 and SD 18.91. The scores on the four subscales of the Internalized HIV stigma Measure were also categorized into three levels (Low IHS, Moderate IHS and high IHS). As was the case in Overall IHS score, those falling under the Moderate level formed the highest proportion in two subscales i.e., Stereotypes of HIV (66%) and Self-acceptance (42%). In the other two subscales, i.e., HIV Disclosure Concerns and Social Relationships Stigma, more than half of the participants (52% and 54% respectively) fall under the low level.

Statistical analysis (Table 4) shows that there is a significant gender difference in IHS, with females scoring higher than males ($p<0.05$). Results also showed that there are significant differences in IHS, on the basis of duration of diagnosis ($p<0.01$) and occupation ($p<0.01$).

Quality of Life among PLWHA in Aizawl: The level of Quality of Life among PLWHA is presented in Table 5. The highest proportion of the sample (52%) falls under the Moderate level of Quality of Life. Those experiencing High Quality of Life form the smallest proportion (16%), while 32% of the participants fall under the Low Quality of Life level. The mean Quality of life score was found to be 76.76 and SD 12.28. The scores on the six domains of the WHOQOL-HIV BREF were also categorized into three levels (Low QOL, Moderate QOL and High QOL). As was the case in Overall QOL score, those falling under the Moderate level formed the highest proportion in all the six domains i.e., physical health (54%), psychological health (50%), level of independence (40%), social relationships (42%), environment (52%), and spirituality/religion/personal beliefs (44%).

Non-parametric statistics were used to analyzeQuality of Life, on the basis of the different socio-demographic variables. No significant differences were found in Overall Quality of Life, based on any of the socio-demographic variables.

Internalized HIV Stigma and Quality of Life: Table 6 shows the correlation coefficients between Internalized HIV Stigma and Quality

of Life of PLWHA. IHS of PLWHA was significantly and negatively correlated with their overall QOL ($p<0.01$). It was also significantly and negatively correlated with five domains of QOL: Physical Health ($p<0.01$), Psychological Health ($p<0.01$), Level of independence ($p<0.01$), Environment ($p<0.05$) and Spirituality ($p<0.01$). The overall QOL was also significantly and negatively correlated with three subscales of IHS Measure: HIV Disclosure Concerns ($p=0.01$), Social Relationships Stigma ($p<0.01$) and Self-acceptance ($p<0.01$).

The overall Internalized Stigma scores were significantly and positively correlated with its four subscales. Similarly, the overall Quality of Life was significantly and positively correlated with its six domains.

Correlation coefficients between the four subscales of the Internalized HIV Stigma Measure and the six domains of WHOQOL-HIV BREF were also analyzed. No significant correlation was found between Stereotypes of HIV and the six domains of QOL. However, HIV Disclosure Concerns was significantly and negatively correlated with Psychological Health ($p<0.01$), Environment ($p<0.05$) and Spirituality ($p<0.01$). Social Relationships Stigma was also significantly and negatively correlated with Level of independence ($p<0.01$), Social Relationships ($p<0.01$) and Spirituality ($p<0.01$). Self-acceptance was significantly and negatively correlated with four domains: Physical health ($p<0.01$), Psychological health ($p<0.01$), Level of independence ($p<0.01$) and Spirituality ($p<0.01$).

Table 1: Age, Gender, Duration of Diagnosis, Religion, Marital Status and Number of Children of PLWHA

AGE	Frequency (Percent)
20 to 25 years	1 (2%)
26 to 30 years	16 (32%)
31 to 35 years	15 (30%)
36 to 40 years	12 (24%)
41 to 45 years	4 (8%)

above 45 years	2 (4%)
GENDER	
Male	24 (48%)
Female	26 (52%)
DURATION OF DIAGNOSIS	
1 Year	8 (16%)
2 to 5 years	17 (34%)
6 to 9 years	17 (34%)
10 years or more	8 (16%)
RELIGION	
Christian	50 (100%)
MARITAL STATUS	
Single	8 (16%)
Married	26 (52%)
Divorced	10 (20%)
Widow	6 (12%)
NUMBER OF CHILDREN	
0	15 (30%)
1	16 (32%)
2	10 (20%)
3	6 (12%)
4	3 (6%)

Table 2: Educational Qualification, Occupation and Income of PLWHA

EDUCATIONAL QUALIFICATION	Frequency (Percent)
Illiterate	2 (4%)
Primary	4 (8%)
Middle	15 (30%)
High School	17 (34%)
Higher Secondary School	8 (16%)
BA	4 (8%)

INCOME (Rs.)	
No income	11 (22%)
Below 3000	18 (36%)
Between 3000 and 6000	15 (30%)
Between 6000 and 9000	1 (2%)
Between 9000 and 12000	4 (8%)
Above 12000	1 (2%)
OCCUPATION	
Unemployed	8 (16%)
Manual labour	19 (38%)
Govt. Servant	2 (4%)
Social worker	16 (32%)
Mechanic	1 (2%)
Tailoring	1 (2%)
Business	3 (6%)

Table 3: Prevalence and levels of Internalized HIV Stigma among PLWHA

Level of Internalized HIV Stigma	**Frequency**	**Percent**
Low	17	34
Moderate	26	52
High	7	14
Total	**50**	**100**
Internalized HIV Stigma Subscales:	**Frequency**	**Percent**
Stereotypes of HIV		
Low	7	14
Moderate	33	66
High	10	20
HIV Disclosure Concerns		
Low	26	52
Moderate	10	20
High	14	28

Social Relationships Stigma		
Low	27	54
Moderate	17	34
High	6	12
Self-acceptance		
Low	17	34
Moderate	21	42
High	12	24
Overall Internalized Stigma Score	**Minimum**	**Maximum**
	4.91	85.51
	Mean	SD
	43.89	18.91

Table 4: Demographics and Internalized HIV Stigma

Demographic Characteristics	**Low Stigma**	**Moderate Stigma**	**High Stigma**	**Mann Whitney U (p value)**
Gender				**<0.05**
Male	11	12	1	
Female	6	14	6	
Duration of Diagnosis				**<0.01**
< or = 1	0	7	1	
2 - 5 yrs	1	13	3	
6 - 9 yrs	10	5	2	
> or = 10 yrs	6	1	1	
Occupation				**<0.01**
Unemployed	0	5	3	
Manual Labour	3	12	4	
Govt. Servant	1	1	0	
Social Worker	12	4	0	
Mechanic	1	0	0	
Tailor	0	1	0	
Business	0	3	0	

Table 5: Quality of Life among PLWHA

Level of Quality of Life	Frequency	Percent
Low	16	32
Moderate	26	52
High	8	16
Total	50	100
Quality of Life Domains	Frequency	Percent
Physical Health		
Low	12	24
Moderate	27	54
High	11	22
Psychological Health		
Low	19	38
Moderate	25	50
High	6	12
Level of Independence		
Low	14	28
Moderate	20	40
High	16	32
Social Relationships		
Low	8	16
Moderate	21	42
High	21	42
Environment		
Low	16	32
Moderate	26	52
High	8	16
Spirituality/Religion/Personal Beliefs		
Low	12	24
Moderate	22	44
High	16	32
Overall Quality of Life Score	Minimum	Maximum
	55.4	102.6
	Mean	SD
	76.76	12.28

Table 6: Correlations among Internalized HIV Stigma and Quality of Life

Spearman's Correlation Co-efficients											
	Stereotypes of HIV	HIV Disclosure Concerns	Social Relationships Stigma	Self-Acceptance	Quality of Life	Physical Health	Psychological Health	Level of independence	Social Relationships	Environment	Spirituality/Religion/Personal beliefs
Internalized HIV Stigma	.488**	.869**	.598**	.796**	-.440**	-.380**	-.454**	-.337*	-0.221	-.283*	-.415**
Stereotypes of HIV		0.275	.325*	0.176	-0.163	-0.153	-0.16	-0.177	-0.217	-0.022	-0.069
HIV Disclosure Concerns			.293*	.671**	-.356*	-0.248	-.434**	-0.13	-0.087	-.305*	-.452**
Social Relationships Stigma				.308*	-.418**	-.402**	-0.237	-.463**	-.408**	-.407**	-0.192
Self-Acceptance					-.453**	-.371**	-.506**	-.377**	-0.176	-0.236	-.428**
Quality of Life						.734**	.779**	.810**	.668**	.702**	.665**
Physical Health							.523**	.633**	.400**	.389**	.341*
Psychological Health								.597**	.478**	.577**	.437**
Level of independence										.428**	.394**
Social Relationships										.670**	0.232
Environment											.309*
Spirituality/Religion/Personal beliefs											

*p ≤0.05
**p≤0.01

DISCUSSION

This was a baseline study among PLWHA in Aizawl that determined the prevalence of Internalized HIV stigma and its association with Quality of Life. No other psychological studies have been carried out in Aizawl on PLWHA. Despite efforts in addressing stigma and discrimination, 14% of PLWHA had experienced high levels of overall Internalized stigma and 28%, 28%, 12% and 24% of them continue to experience high levels of Stereotypes of HIV, Disclosure Concerns, Social Relationships stigma and Self-acceptance respectively. High disclosure-related concerns are supported by quantitative studies of stigma (Thomas et al. 2005, 797; Subramanian et al. 2009).

In this study, overall stigma was reported higher among females in this study. Significant gender differences were also found in HIV Disclosure Concerns, Social Relationships stigma and Self-acceptance. The finding that there is a significant gender difference in Internalized HIV stigma among PLWHA is similar to a study undertaken among PLWHA in Puerto Rico where women showed significantly higher levels of HIV-related felt stigma than did men (Jiménez et al. 2012, 67).However, a study in Bangladesh revealed that male PLWHA were more likely to experience high IHS compared to the female PLWHA (Hasan et al. 2012, 26).

Moreover, Internalized HIV stigma was higher among those diagnosed within the past five years, which suggests that it decreases as time progresses. A significant difference in Internalized HIV stigma was also found on the basis of occupation, with Internalized HIV stigma higher in those who were unemployed or manual labourers.

This study reported poor QOL among 32% of participants. QOL was markedly affected in Psychological health (poor QOL 38%) as compared to other domains such as physical (24%), social (16%) and spirituality (24%).These findings are similar to those of other studies in South India which also reported poor QOL in different domains (Kohli et al. 2005, 1643-1644; Nirmal et al. 2008, 16; Charles et al. 2012, 5).

In this study, no significant differences were found in Overall Quality of Life, based on age, gender, duration of diagnosis, religion, marital status, number of children, educational qualification, occupation and income. However, significant gender differences were found in Psychological health, Environment and Spirituality. Females have reported lower scores in Psychological health, Spirituality and in the Environment domain, than males. This finding is similar to that of another study where females were found to be lower in many domains of QoL (Kohli et al. 2005, 1644). Also, a significant difference in Psychological Health was found on the basis of the number of children, with more participants having children falling in the Low level. In Social Relationships Domain, it was found that those with higher Educational Qualifications scored higher.

According to this study, there was a significant negative relationship between Internalized HIV stigma and Quality of Life among PLWHA in Aizawl, i.e., the higher the level of Internalized stigma, the lower is the Quality of Life, and vice versa. This finding is similar to a study conducted in Chennai, where stigma was found to have a significant negative correlation with QOL (Thomas et al. 2005, 799).

Three subscales of Internalized stigma (Disclosure Concerns, Social Relationships Stigma and Self-Acceptance) were found to be negatively correlated with overall QOL. PLWHA who were found to have disclosure concerns had poor QOL in psychological health, spirituality and the environment domain. This finding is similar to that of a study by Charles et al. 2012, where severe disclosure domains were found to be correlated with poor QOL in the Environmental domain. Social Relationships Stigma was found to have negative correlations with Physical Health, Level of independence, Social relationships and Environment Domains of QOL. Self-acceptance was also negatively correlated with Physical Health, Psychological health, Level of independence, and Spirituality. On the contrary, a study showed that respondents who reported of actual stigma (33%) had significantly good QoL in their physical domain (49%), psychological domain (48%) and environmental domain (44%) (Subramanian et al. 2009).

As this study is cross sectional, it is difficult to prove causal relationships. The sampling procedure was dependent on the members of various PLWHA networks. The proportion of PLWHA who are not members of these networks, and those who have not disclosed their HIV status so far is unknown. In addition, PLWHA aged between 20-50 years, who provided informed consent and were not too sick to answer the questions alone were included in the study. Thus, our findings may not represent the entire PLWHA in Aizawl.

CONCLUSION

In summary, this baseline study found a prevalence of High Internalized Stigma of 14% and poor overall QOL of 32%. Internalized HIV stigma and Quality of Life were significantly and negatively correlated. Several studies in India have also reported the association between stigma and the Quality of Life. HIV/AIDS stigma can severely compromise the quality of life of people living with this condition by reducing access and quality of care. Thus, stigma may prove to be a barrier in optimizing the Quality of Life of PLWHA and this issue needs to be addressed by policy makers and treatment and service providers.

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Abbreviations:

AIDS	-	Acquired immunodeficiency syndrome
HIV	-	Human immunodeficiency virus
PLWHA	-	People living with HIV/AIDS
IHS	-	Internalized HIV Stigma
QOL	-	Quality of Life
WHO	-	World Health Organization
IDU	-	Intravenous drug Users
CSW	-	Commercial Sex Workers
NACO	-	National AIDS Control Organization
MSACS	-	Mizoram State AIDS Control Society